



Supported Living; It's a New Direction

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Our understanding of what it means to support individuals with autism and other developmental disabilities to live in the community changes over time. Since the beginning of the deinstitutionalization movement in the 1970s, we have seen the development of increasingly smaller residential facilities, with group homes becoming popular in the 1980s. This trend continues across the country. In fact, a majority of people receiving Mental Retardation/Developmental Disability residential services live in homes of 6 or fewer people now; many of them live in homes of 3 or less (Prouty & Lakin, 1996).

A critique of the current service system, however, is that people considered to have the most severe disabilities, and often people with autism, tend to remain in the largest and most restrictive settings (Prouty & Lakin, 1995). Furthermore, from the perspective of people with disabilities, even a small group home can be similar to living in an institution (Bercovici, 1983; Kennedy, 1994). People continue to be segregated and have limited control over their lives. Since the mid 1980s, there has been a movement to support individuals to live in their own homes, become members of their communities, and to have greater control over their lives and the assistance they receive, regardless of their disability. This approach is referred to as supported living and is based on the philosophy that even though people may have needs specific to their disability, these needs should not interfere with the opportunity for basic life experiences such as physical and social integration, choice, and respect (O'Brien, 1987). Increasing numbers of individuals and their families are requesting supported living services and several agencies around the state of Indiana have recently adopted the approach.

This approach is particularly responsive to the many individuals with autism who have difficulty with unpredictability, inconsistency, commotion, and communication. The opportunity to live in their own home and to choose who they live with, who provides their support, and what activities and routines to follow has led to significant improvements in people's behavior and sense of satisfaction (Hulgin, 1996). As successful situations are developed, our vision of what people need and what is possible is expanding.

Moving toward this vision will require a great deal of change. Policies, funding, and practices are designed to provide services in institutions and other congregate settings. This is evident by the fact that an overwhelming majority of individuals with autism in Indiana currently live in settings of 6 or more people (see Table on page 4). The opportunity for individuals to live in their own homes will depend upon the following changes.

- Individuals with autism and their families need the opportunity to learn about supported living as an alternative approach to congregate services. It is not enough to simply ask an individual where they want to live. Many individuals need experience, the opportunity to explore their preferences, and input from people who know them well to make such decisions. Families also need the opportunity to learn. They often have concerns and even fears that their family member will not receive the support they need if they live in a home of their own. They have come to believe that it is only appropriate or possible for those who acquire the skills to live independently. Individuals and families can learn from situations in which others have been successfully supported to live in their own homes.
- Service agencies will need to make fundamental changes in the way they are organized to provide supported living services. This approach requires an organization to be personal, flexible, and innovative. It requires change in organizational structures and staff roles and responsibilities. Such change is difficult to implement in agencies

that are heavily invested in providing congregate services and will take a great deal of commitment and time.

- As individuals, their families, and service providers figure out what it takes to support people to live in their own homes, they are identifying barriers within the current system. Several changes in policy and funding are essential to the development of supported living such as:
 - expanding our state's utilization of the Medicaid Home and Community Based Waiver;
 - removing state imposed limitations on the cost of services for individuals as opposed to the use of an average; and
 - and redirecting resources from institutional and congregate services.

Though the development of community services has been associated with the move toward smaller group settings, supported living represents a radically new direction. As the opportunity to live in one's own home and become a valuable member of the community is becoming the expectation of a growing number of individuals and their families, we will all be challenged to make significant changes.

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